# Fetal Alcohol Spectrum Disorders

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# Fetal Alcohol Spectrum Disorders (FASD): The Basics

- 1. Understanding Fetal Alcohol Spectrum Disorders (FASD)
- 2. Individuals With An FASD Strengths, Difficulties, and Approaches
- 3. Prevention and Risk Reduction
- 4. Resources & Conclusion

# What do you know?

### Understanding Fetal Alcohol Spectrum

#### Disorders(FASD)

- Fetal Alcohol Spectrum Disorders (FASDs)
- Diagnostic Terminology
- Facts About FASDs
- Facts About Alcohol Use Among Pregnant Women
- Cause of FASDs
- What's a Standard Drink?
- Economic Costs of FAS

## Diagnostic Terminology

Fetal Alcohol Syndrome (FAS)

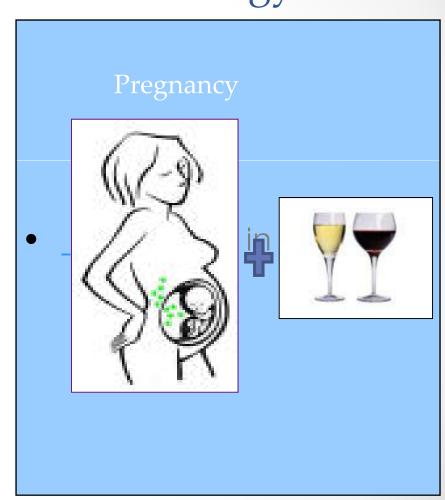
- •The term FAS was first used in 1973 by Dr. David Smith and Dr. Ken Lyons Jones at the University of Washington.
- While FASD describes a range of disorders, FAS is a specific birth defect caused by alcohol use while pregnant.
  - FAS *is* a diagnosis: It is medical diagnosis Q86.0 in the International Classification of Diseases (ICD-10).

## Fetal Alcohol Spectrum Disorders (FASD)

- Umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy.
- May include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.
- Not a diagnosis

## Other Diagnostic Terminology

- Alcohol-related neurodevelopmental disorder (ARND)
- Partial FAS (pFAS)
- Fetal alcohol effects (FAE)
- Alcohol-related birth defects (ARBD)
- Static encephalopathy (an unchanging injury to the brain)



#### Facts About FASDs

- FASDs are the leading known cause of preventable mental retardation.<sup>1</sup>
- FASDs effect an estimated 40,000 newborns each year in the United States.<sup>2</sup>
- FASDs are more common than autism.<sup>3</sup>
- The effects of FASDs last a lifetime.
- People with an FASD can grow, improve, and function well in life with proper support.
  - FASDs are 100% preventable.

#### Facts About FASDs

- No amount of alcohol consumption during pregnancy is proven to be safe.<sup>1</sup>
- FASDs are not caused by the biological father's alcohol use.
  - FASDs are not caused intentionally by the mother: Many women simply may not know when they are first pregnant or may not be aware of the harm that alcohol consumption during pregnancy can cause

#### Facts About Alcohol Use

## Among Pregnant Women

- Nearly 12 percent of pregnant women report using alcohol in the past month.
- Past-month alcohol use among pregnant women and recent mothers aged 15 to 44 did not change significantly between 2002-2003 and 2006-2007.
- Nearly 16 percent of pregnant women aged 15 to 17 used alcohol in the past month, and they consumed an average of 24 drinks in that month (i.e., they drank on an average of 6 days during the past month and had an average of about four drinks on the days that they drank).

# Cause of FASDs

- The sole cause of FASDs is the fetus being exposed to alcohol during the pregnancy.
- Alcohol is a teratogen: A drug or other substance capable of interfering with the development of a fetus, causing birth defects.

"Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus."

—IOM Report to Congress, 1996

## Cause of FASDs

- All alcoholic beverages are harmful.
- Binge drinking is especially harmful.\*
- While it's true that not every woman who drinks during pregnancy will have a child with an FASD, that does not mean that these disorders are rare or random.
- Any time a pregnant woman consumes alcohol, it becomes possible that her baby will have an FASD.
  - \* Binge = 4 or more standard drinks on one occasion for women

# What's A Standard Drink?

12 oz. of beer or cooler	8–9 oz. of malt liquor 8.5 oz. shown in a 12-oz. glass that, if full, would hold about 1.5 standard drinks of malt liquor	5 oz. of table wine	3-4 oz. of fortified wine (such as sherry or port) 3.5 oz. shown	2–3 oz. of cordial, liqueur, or aperitif 2.5 oz. shown	1.5 oz. of brandy (a single jigger)	1.5 oz. of spirits (a single jigger of 80-proof gin, vodka, whiskey, etc.) Shown straight and in a highball glass with ice to show the level before adding a mixer*
-5% alcohol	-7% alcohol	-12% alcohol	-17% alcohol	-24% alcohol	-40% alcohol	-40% alcohol

#### What's a Standard Drink?

In recent research, frequent drinkers and the majority of women reported drinking larger-than-standard drinks:

- Daily drinkers were consuming drinks that were anywhere from three to six times the size of a standard drink.
- The majority of drinkers underestimated the number of fluid ounces they were consuming by about 30%.

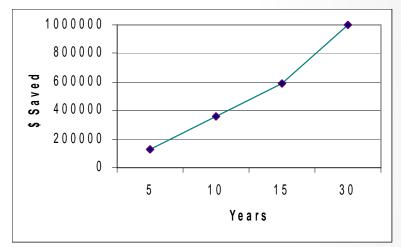
#### **Economic Costs of FAS**

- FAS alone is estimated to cost the United States nearly \$4 billion each year.
- The average lifetime cost for each child with FAS is almost \$3 Million.



#### **Economic Costs of FAS**

- One prevented case of FAS saves:
  - \$130,000 in the first 5 years
  - \$360,000 in 10 years
  - \$587,000 in 15 years



**Increased Savings through Prevention** 

More than \$1 million in 30 years

# Individuals With an FASD – Strengths, Difficulties, and Approaches

- Primary Disabilities That Can Occur in Persons With an FASD
- Typical Strengths of Persons With an FASD
- Typical Difficulties for Persons With an FASD

# Typical Strengths of Persons With an FASD

Friendly and cheerful

Likable

Desire to be liked

Helpful

Verbal

Determined

Have points of insight

Hard working

Every day is a new day!

# Typical Difficulties For Persons With an FASD

Sensory: May be overly sensitive to bright lights, certain clothing, tastes and textures in food, loud sounds, etc.



• Physical: Have problems with balance and motor coordination (may seem "clumsy").

# Typical Difficulties For Persons With an FASD

#### Information Processing:

- Do not complete tasks or chores and may appear to be oppositional
- Have trouble determining what to do in a given situation
- Do not ask questions because they want to fit in
- Have trouble with changes in tasks and routine.

# Typical Difficulties For

#### Persons With an FASD

- Information Processing
- Have trouble following multiple directions
- Say they understand when they do not
- Have verbal expressive skills that often exceed their verbal receptive abilities
- Cannot operationalize what they've memorized (e.g., multiplication tables)
- Misinterpret others' words, actions, or body movements

How do I

Straighten

√v room?

# Typical Difficulties For

#### Persons With an FASD

### **Executive Function and Decision-Making**

- Repeatedly break the rules
- Naïve, gullible (e.g., may walk off with a stranger)
- Struggle with abstract concepts (e.g., time, space, money, etc.)
- Have difficulty entertaining themselves
- Give in to peer pressure
- Tend not to learn from mistakes or natural consequences
- Frequently do not respond to reward systems (points, levels, stickers, etc.)





# Typical Difficulties For

#### Persons With an FASD

#### Self-Esteem and Personal Issues:

- Function unevenly in school, work, and development – Often feel "stupid" or like a failure
- Are seen as lazy, uncooperative, and unmotivated
   –Have often been told they're not trying hard enough
- May have hygiene problems
- Are aware that they're "different" from others
- Often grow up living in multiple homes and experience multiple losses

# Risks of Not Accurately Identifying and Treating an FASD

#### For the individual with an FASD:

- Unemployment
- Loss of family
- Homelessness
- Jail
- Premature death
- Increased substance abuse
- Wrong treatment or
- intervention is used

## For the family:

- •Loss of family
- Increased substance use
- •Premature death
- •Financial strain
- Emotional stress

# Factors Associated With Reduced Life Complications

- Stable home
- Early diagnosis
- No violence against oneself
- More than 2.8
   years in each living
   situation

- Recognized disabilities
- Diagnosis of FAS
- Good quality home from ages 8 to 12
- Basic needs met for at least 13 percent of life

## Identifying an FASD

Only trained professionals can diagnose a disorder from the FASD spectrum. Ideally, diagnosis is done by a team that may include:

- > Geneticists
- > Developmental pediatricians
- > Neurologists
- Dysmorphologists (physicians specializing in birth defects)
- > Education consultants
- > Psychologists, psychiatrists, and social workers
- > Occupational therapists
- > Speech and language specialists

## Possible Signs of an FASD

# Signs that may suggest the need for FASD assessment include:

- > Sleeping, breathing, or feeding problems
- > Small head or facial or dental irregularities
- > Heart defects or other organ dysfunction
- > Deformities of joints, limbs, and fingers
- > Slow physical growth before or after birth
- > Vision or hearing problems
- > Mental retardation or delayed development
- > Behavior problems
- > Maternal alcohol use

#### Trends in Treatment

Strategies to assist persons with an FASD and their families continue to increase dynamically:

- SAMHSA's FASD Center for Excellence provides a variety of materials for families, providers, and<sub>e</sub> ducators:
- In addition to materials, the National Organization on Fetal Alcohol Syndrome (NOFAS) provides a directory of FAS resources: <a href="www.nofas.org/resource/directory.aspx">www.nofas.org/resource/directory.aspx</a>
- The Centers for Disease Control and Prevention (CDC) are currently researching new approaches to FASD at sites across the country.

# Conclusion

 The Benefits of Identification and Treatment of FASDs

What is Needed

# The Benefits of Identification and Treatment of FASDs

- Helps decrease anger and frustration for individuals, families, providers, and communities by helping them understand that negative behavior results from the disability and is not willful.
- Helps people with an FASD succeed by focusing on their strengths and what will help them, not on their 'weaknesses' and what they've done 'wrong.'
- Helps improve outcomes.
- Helps prevent future births of children with an FASD.



#### What is Needed

• What is needed to adequately address FASDs is a paradigm shift in how we think:

"We must move from viewing the individual as failing if she does not do well in a program to viewing the program as not providing what the individual needs in order to succeed."

—Dubovsky, 2000

# Thank you for taking time to learn about FASDs!

For more information about FASDs, including topics such as diagnosis and treatment, please visit http://www.fascenter.samhsa.gov.